**Women with self-reported lower limb lymphoedema after treatment for gynaecological cancers: are they more likely to self-report psychosocial symptoms and less likely to use services?**

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**Abstract**

**Background:** Due to improved screening and treatment for gynaecological cancers survivorship has increased. Use of supportive care services after treatment is important to improve quality of life.

**Objective:** To assess self-reported lower-limb lymphoedema (LLL), depression, anxiety, quality of life, unmet supportive care needs, and service use among gynaecological cancer survivors.

**Methods:** In 2010 a population-based cross-sectional mail survey was conducted (n=160 gynaecological cancer survivors 5 to 30 month post-diagnosis (53% response rate)).

**Results:** Overall, 30% of women self-reported LLL, 21% and 24% depression or anxiety, respectively. Women with LLL were more likely to also report symptoms of depression or anxiety, and had higher unmet supportive care needs. Services needed but not used by 10-15% of women with LLL, anxiety or depression respectively were lymphoedema specialist, pain specialist and physiotherapist, or psychiatrists, psychologists and pain specialists.

**Limitations:** Small sample size, self-report data, limited generalisation to other countries, underrepresentation of older women (age >70) and women from non-Caucasian backgrounds.

**Conclusions:** Women with LLL or high distress were less likely to use services they needed.

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**Keywords:** gynaecological cancer, supportive care, service use, depression, anxiety, lymphoedema

**Abbreviations List:**

LLL: lower-limb lymphoedema

QCGC: Queensland Centre for Gynaecological Cancer

RBWH: Royal Brisbane and Women's Hospital

HADS: The Hospital Anxiety and Depression Scale)

SCNS: Supportive Care Needs Survey

FACT-G: Functional Assessment of Cancer Therapy- General

## Introduction

Cancers arising from female reproductive organs account for approximately 18% of all female cancers worldwide. Improved screening and treatments programs have led to increase in survival rates.[1] Research concerning supportive care needs and services after treatment is important to further improve the long-term quality of life of gynaecological cancer survivors. [2,3] Survivors of these cancers are likely to need good access to supportive care to help them with problems specifically related to gynaecological cancer treatment such as lower-limb swelling or lymphoedema (LLL), problems with sexuality and impaired fertility, premature menopause, bladder dysfunction, depression and anxiety. [1,3,4] Wide estimates of the prevalence of LLL after treatment for gynaecological cancer have been reported ranging from 5 to 70%. [5-12] The prevalence of LLL appears highest after treatment for vulvar cancer (36-47%) and lowest after ovarian cancer (4-7%).[7] Evidence suggests that most cases of LLL will develop in the first 24 months after treatment, especially in those women who had lymph node dissection and/or radiation therapy.[7,11,12] Women with LLL may experience a range of other physical symptoms apart from swelling such as heaviness, pain and discomfort, which can lead to physical dysfunction and inability to perform daily activities.[7] LLL has also been associated with sexual, social, financial and psychological problems,[6,9] which in their accumulation have been reported to lower quality of life and increase unmet supportive care needs.[7]

Similar to LLL, the reported prevalence of depression (6 to 58%) and anxiety (20 to 53%) among gynaecological cancer survivors varies widely across studies. [3,13-17] Younger age, pessimism, being Caucasian, physical impairment, unsupportive family and friends, higher stage of cancer, and recent diagnosis of cancer are factors that have been associated with higher levels of psychological distress. [3,15,18] Women who use avoiding coping strategies including self- blame and wishful thinking have also been reported to experience higher levels of psychological distress. [15] Women with high levels of psychological distress have been found to have a poorer compliance with treatment, and lower quality of life compared to women with lower distress levels. [19] Gynaecological cancer survivors with depression and anxiety are also more likely to report unmet supportive care needs. [14,17]

While the supportive care needs of women with LLL, depression or anxiety have been studied in isolation little research has assessed these symptoms and their effect on supportive care needs and service use after gynaecological cancer simultaneously.[6,7,14,17,19] Besides describing the prevalence of LLL, anxiety and depression among gynaecological cancer survivors, this study aimed to determine factors associated with these conditions as well as those associated with not using available and needed services to alleviate these conditions.

## Methods

This study was conducted at the Queensland Centre for Gynaecological Cancer (QCGC) located at the Royal Brisbane and Women's Hospital (RBWH), in Australia. Potentially eligible women were selected from the records in the QCGC Registry. Eligibility criteria included being diagnosed with gynaecological cancer at least 5 months and no more than 30 months prior to the study date, female, 18 years of age or over and providing written informed consent. Exclusion criteria were not being able to understand or write English or mental impairment. Overall, 327 potential participants met the eligibility criteria, and were sent a letter from the Director of Research QCGC inviting their participation in the study. Of these, 173 patients (response rate 53%) provided written informed consent and mailed back their questionnaires. Data was incomplete for 13 patients, and 160 complete questionnaires were included in analysis. The data manager extracted information from the cancer registry about the participants' age, cancer diagnosis (type and stage) and treatment information (treatments received). Ethical approval was obtained from RBWH Human Research Ethics Committee.

### *Materials*

The questionnaire included the following items:

*Demographic characteristics* including age, marital status, income, education and employment.

*The Gynecologic Cancer Lymphoedema Questionnaire* was utilised to measure symptoms of lymphoedema in the past 4 weeks. This 20-items self-administered questionnaire assesses various aspects of leg heaviness, swelling, infection, numbness and physical functioning. The questionnaire is a reliable tool with a good sensitivity and specificity for LLL if the patient reports four or more symptoms of lymphoedema. [20]

*The Hospital Anxiety and Depression Scale (HADS)* is a reliable and valid self-administered screening tool of anxiety and depression particularly suitable for cancer populations. [21,22] *The short form of the Supportive Care*

*Needs Survey (SCNS-SF34)* was used to determine the number of unmet supportive care overall and within the five domains of psychological, physical and daily living, patient care/support and sexuality needs. The survey is a validated measurement tool specifically developed for cancer populations. [23] In addition, patients completed the *Need for services module of the* SCNS. The first five questions of the module, related to hospital facilities were omitted, because the women were at least 5 months post diagnosis.

*The Functional Assessment of Cancer Therapy- General (FACT-G)* was used to measure quality of life in physical, social, functional and emotional well-being domains. The FACT-G is a validated measurement tool widely used in cancer populations. [24]

*Statistical analyses*

Descriptive statistics were used to summarise participants' demographic and clinical characteristics, as well as prevalence of LLL, depression and anxiety. For the purpose of this report we define LLL if women self-reported swelling and an additional three or more other leg symptoms according to Carter et al.[20] To define high levels of anxiety and depression a HADS cut-off level of 8 points was used as described by Bjelland et al. [21]

Chi-Square tests and logistic regression analyses were used to explore the associations between LLL, depression or anxiety and demographic and clinical patient characteristics. Those found to be associated at p-value <0.2 were entered into multivariable logistic regression models to determine the independent factors associated with each of the outcome variables. For continuous variables t-tests were used to compare the means of women with or without LLL depression or anxiety. We plotted the proportions of women with/ without LLL, high levels of depression/ anxiety against their need for and use of services to establish whether services reached the women of greatest need. We created a variable of psychological distress for women who had high scores of anxiety and or depression (>8) on the HADS. We grouped women by whether they reported a need for a service but had not used it and conducted multivariable logistic regression to establish factors associated with not using services as needed, entering distress, LLL, sociodemographic and clinical details by forced entry retaining those with significant contribution only. A standard p-value of 0.05 was used.

**Results**

*Sample*

The majority of participating women were older than 50 years (80%) with a mean age of 61 (59-63) years. Most women were treated for endometrial cancer (49%) and few women were treated for vulval cancer (6%). Sixty-seven percent were married or lived together with a partner. Surgery was the main treatment received by 88% of the women, chemotherapy by 44% and radiotherapy by 22%. The prevalence of self-reported LLL was 30%. High levels of depression or anxiety were reported by 21% and 24% of women, respectively. (Table 1) Depression (29%) or anxiety (31%) were more commonly reported by women with LLL than those without LLL (19% and 21%, respectively).

*Impact of LLL*

Women with LLL had significantly higher mean scores of unmet needs in psychological (p=0.01), physical and daily living (p=0.04), health needs (p= 0.02) and patient care needs (p=0.02) in comparison to women without LLL. These women also had a significantly lower physical well-being (p=0.008) compared to survivors without LLL. Functional well-being (p=0.08) and overall quality of life (p=0.08) were also somewhat worse in women with LLL, but only achieved borderline significance.

*Use of services*

Women with LLL needed more services in every domain, especially a lymphoedema specialist (34%), physiotherapist (37%), psychologist (23%), exercise physiologist (21%) and dietician (21%). Fifteen percent of the women with LLL needed but did not use the service of a lymphoedema specialist and 10% needed but did not use a physiotherapist and/or a pain specialist (Table 2).

*Impact of depression/anxiety*

Women without a partner were somewhat more likely to have higher depression levels (p=0.06). Older women (age >70 years) were less likely to report higher levels of anxiety (p=0.04). Participants who were unemployed (p=0.01, 0.02) or retired (p=0.02, 0.07) reported higher levels of depression and anxiety, respectively. Of these factors being unemployed (OR: 11.34, CI: 2.12- 60.45, p<0.01) and being retired (OR: 10.82, CI: 2.08- 56.31, p=0.01) remained independently significant associated with high levels of depression in multivariable analyses.

Older age (OR: 0.29, CI: 0.13- 0.64, p<0.01), being unemployed (OR: 5.80, CI: 1.56- 21.51, p=0.01) and retired (OR: 7.77, CI: 2.15- 28.07, p=0.01) remained independently significant in women with high levels of anxiety in multivariable analyses. Women with high levels of depression/anxiety had significantly higher mean scores of unmet needs than women with low levels of depression/anxiety in all domains: psychological (p=<0.01), physical and daily living (p=<0.01), health needs (p= <0.01), patient care (p=<0.01) and sexuality (p=<0.01). Women with high levels of depression/ anxiety had significantly lower quality of life in all domains: physical (p=<0.01), social- family (p=<0.01), emotional (p=<0.01), functional (p=<0.01) and total well- being (p=<0.001).

*Use of services*

Women with high levels of depression needed more services in every domain in comparison with women with low levels of depression. The women needed but did not use a psychologist (23%), psychiatrist (18%) and a pain specialist (21%). Women with high levels of anxiety needed more services in every domain in comparison to women with low levels of anxiety. The women needed but did not use a pain specialist (26%), psychologist (24%), lymphoedema specialist (18%) and psychiatrist (18%) (Table 2).

*Factors associated with unused services*

In bivariate analyses women with psychological distress (p<0.01) were more likely to need but not use services, while women treated with radiotherapy (p=0.03) were less likely to need but not use services. Of these factors psychological distress (OR: 6.52, CI: 2.79-15.23, p<0.01) remained independently significant in multivariable analyses.

**Discussion**

In this study women with LLL, or those with elevated level of depression and anxiety after treatment for gynaecological cancer had higher supportive care needs and reported lower quality of life in comparison to women without LLL, depression and anxiety. Having experienced LLL also meant that women were more likely to report psychosocial distress. Women with these sequelae needed more services than other women, but a substantial proportion (10-15%) did not use them. The only factor independently associated with not using

needed services was depression. Similar to this study, previous studies have also found higher unmet supportive care needs and lower quality of life in women with LLL, depression and anxiety. [6,7,14,17,19] Our study expands on previous studies by assessing services needed and used and factors associated with not using services.

Clinical (such as tumour type) or demographic factors (such as age) were expected to be associated with service need and use, however the only factor to be associated with not using needed services to alleviate symptom burden was psychological distress. Interestingly, use of services was not different depending on women's distance to their regular general practitioner, which indicates that other reasons than immediate access need to be explored in future studies as barriers to service use. It may be that women with psychological distress tend to use problem-focused or avoiding coping strategies, making them less likely to attend services even if they are available.[15] Beesley et al. found that women with greater psychological stress utilised more information/internet support and suggested that they may therefore not seek sufficient emotional support/help. [6,15] Online support services have been tested for their ability to lower psychological distress by providing online group support sessions or one-to-one counseling sessions with psychologists. These online support services have been found to reduce psychological distress, pain and improve quality of life and coping. [25-28] Further testing of such online services for women with high symptom burden could provide evidence whether needs can be met without physical contact with a healthcare provider, it can be suspected that this would be less likely for physical ailments.

The prevalence of LLL in this sample was 30%, which corresponds to prevalence rates in previous reports. [5-12] However as noted in the introduction, there is a large variability in reported prevalence rates due to differences in measurements used and proportion of women with different types of gynaecological cancers included. This study utilised the *The Gynecologic Cancer Lymphoedema Questionnaire* which was specifically developed for this population, and is thus likely to accurately report LLL. Services needed and not used by a relatively large proportion of women with LLL were lymphoedema specialist, pain specialist and physiotherapist (10-15% of women needed but did not use these services), and the reason for these women with high needs not using available services should be investigated in future studies.

The prevalence of depression/ anxiety in our sample was 21% and 24%, respectively, similar to those reported in other studies. [3,13-17] Although needed, approximately 15-20% of women with high levels of depression and

anxiety did not use psychiatrist, psychologist and pain specialist, and women with high levels of anxiety also needed but did not use a lymphoedema specialist indicating that distress can also impede women getting the support for physical ailments. Women with high levels of depression/anxiety were more likely to be unemployed and retired, but older age appeared to be protective against high levels of anxiety, concordant with previous findings. [15,18] According to the outcomes of this study, still not enough women with physical and psychological sequels are using services. Women reported low quality of life in different domains, which may be due to these unmet supportive care needs and unused services. [29] Previous reports found that awareness of services may be low in cancer patients, even if they are aware, only 40% utilise the services. Service use is strongly correlated with referral from a healthcare provider. [2] However, Steginga et al. found less than one-third of cancer patients reported receiving advice about community support outside the hospital during treatment, and only one-fifth after their treatment. [30] Other potential reasons for low service uptake could include that the available services do not match the women's needs or the out of pocket costs often associated with using allied healthcare services. In a recent international comparison of health care in 11 countries, 55% of Australian patients reported gaps in their discharge planning, 39% reported carrying $1000 or more of out of pocket costs, and 30% reported cost related access problems. [31] There are already guidelines available about optimal psychosocial support for cancer patients, but health care providers have been found to not apply them systematically.[2] This may be due to underestimation of the psychological needs of the cancer patient by nurses and physicians. [19] Okuyama et al. found that oncologists were not able to accurately detect physical symptoms and borderline depression/ anxiety.[32] Distress has been identified as the sixth vital sign in cancer care by the International Psycho-Oncology Society. The value of integrating routine screening for distress is currently being evaluated in several randomised trials. Results to date indicate that such screening leads to more appropriate referral for, and better uptake of psychosocial services. [33-36]

The findings of this study indicate the need to direct services better towards those gynaecological cancer patients who currently underutilize needed services, in particular women with LLL. Additional or alternative service delivery via innovative routes such as telephone, internet or email may assist to increase the service use and service awareness of women with LLL, depression and anxiety following gynaecological cancer treatment.[37] Some important limitations of this study need to be considered when interpreting these results. We did not ask women for preexisting diagnosis of psychiatric conditions, and are thus unable to determine whether the level of distress and unmet needs were higher depending on such preexisting condition. While reflecting the distribution

of gynaecological cancers within Queensland well, the sample size was small with only 160 women overall completing the questionnaire, and only 30% of those women reporting LLL thus limiting the statistical power to detect factors associated with low service use. Furthermore the sample consisted of mostly of Caucasian women with European background (90%) and other ethnicities were not well represented. The survey used self-report to determine LLL, depression and anxiety, and this may not completely overlap with the clinical assessment of these symptoms; however the prevalence rates were similar to previous studies indicating that women accurately reported their symptoms. Older women (age>70) were underrepresented and the prevalence rate of depression and anxiety may therefore be somewhat higher than in previous reports.[15] Results of supportive care needs and service use in this study may be difficult to generalise to other countries, states and territories, because of differences in service provision and access to supportive care. Lastly women who selected to participate may be more outspoken that those who did not respond. If these women were less likely to experience distress, then this would likely cause an underestimation of the prevalence of unmet needs in the present report.

In summary, our study has highlighted the unmet supportive care needs, service needs and quality of life in gynaecological cancer survivors with LLL and high levels of depression/ anxiety. As for the future still more needs to be done to better direct women with high supportive care and service needs towards services, potentially by introducing routine screening for distress [38] or developing survivorship care plans for the women before they are being discharged from the hospital.[39] The focus in the future should be the testing of interventions to prevent development of LLL, depression and anxiety in randomised clinical trials.

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